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ABSTRACT

The document contains two articles based on papers presented at the Annual Meeting of the American Association on Mental Deficiency (Detroit, 1981). The first paper by D. Mott, et al. is titled "Emotional Needs of People with Mental Retardation--A Preliminary Review." Based on discussions held by staff at the Western Carolina Center (Morganton), the authors consider the following hypotheses: the mentally retarded have the same basic emotional needs as nonretarded; the mentally retarded need to develop self-acceptance; the mentally retarded need to have successful life experiences; and the mentally retarded need a positive, rewarding, stimulating, and secure environment. Treatment implications of these hypotheses are discussed. A second article, "Innovative Mental Health Programs for People with Mental Retardation" by H. Benson, Jr. and J. Gilday, describes four innovative programs for retarded/disturbed individuals. The programs mentioned are the John Merck Program (Pennsylvania), Stone House (North Carolina), Rock Creek Foundation (Washington, D.C.), and Harlem Valley Psychiatric Center (New York). The rationale behind preventive measures is examined. (SW)

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EMOTIONAL NEEDS OF PEOPLE WITH MENTAL RETARDATION AND SERVICES TO MEET THOSE NEEDS

A Humanistic Approach

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DEDICATION

THIS BOOKLET IS DEDICATED BY
THE NATIONAL MENTAL HEALTH ASSOCIATION
TO THE
INTERNATIONAL YEAR OF THE DISABLED PERSON.

To increase the participation of disabled persons in our national life and in the lives of other nations the United Nations has designated 1981 the International Year of Disabled Persons. America has long been a world leader in this area, and the United States Council for the International Year of Disabled Persons and our Federal government have already responded to the United Nations challenge.

The U.S. Council for the IYDP was formed by concerned citizens as a nonprofit organization to promote the "full participation" of the 35 million Americans with physical or mental disabilities in our national and community life. The Council cooperates closely with U.S. government agencies and with other public and private organizations.

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Introduction

In the last few years tremendous gains have been made in the field of developmental disabilities and in the technology of habilitation of retarded people. On many occasions, with some exceptions, we have become subsumed in the technology and/or tools of measurement. When progressive concepts, such as normalization and deinstitutionalization, are developed, we sometimes lose the fundamental truths in our need to develop criteria and standards. In addition, too often the interdisciplinary model simply amounts to a group of professionals attempting to piece back together parts of a puzzle that was once a retarded person, often to no avail. Depersonalization and dehumanization can be the results!

Recently, at Western Carolina Center, we have begun an all inclusive process which we hope will allow us to personalize our attention to retarded people without becoming mesmerized by their handicaps or our technical response to their complex needs. We are making an earnest effort, which takes priority and precedence over all our other endeavors, to emphasize what some would disdain as non-scientific: happiness, dignity, security, personal warmth, and the development of a positive self-image.

To such critics, Gary Zukav might have been speaking in his book, *The Dancing Wu Li Master*,[1] where he traced the evolution of quantum relativistic physics of today as he points out that, "It is no longer evident whether scientists really discover new things or whether they create them. Many people believe that discovery is actually an act of creation. If this is so, then the distinction between scientists, poets, painters, and writers is not clear, in fact, it is possible that they are all members of the same family of people whose gift it is by nature to take those things which we call commonplace and represent them to us in such ways that our self-imposed limitations are expanded."

We've begun a Quality of Life study with sections relating to food, the environment, the matter of choice, attachment needs, leisure interests, the rhythm of life, and, most importantly, the emotional needs of handicapped people. A smaller group of our staff over a several year period has spent a large amount of time and energy in reviewing, researching, and becoming more cognizant of the emotional needs of the people we serve. Theirs has at times been a lonely job. As you read these two articles, you will realize that they were labors of love. There have been many critics of their interest and works - some helpful. They have continued pursuit of these matters with active plans to incorporate their findings not only into the Quality of Life study, but, more importantly, into the lives of the residents and the staff of the facility alike.

There is no system of immunization by which retarded people are rendered safe from emotional stress; quite the contrary. But, how many times have you heard your colleagues voice concern over the possiblity that a profoundly retarded person might also be depressed; or that self-injurious behavior might actually be a depressive equivalent? How often have people openly discussed the effects of emotional and environmental stress on retarded people?

I hope these articles will awaken the field of Developmental Disabilities as well as our colleagues elsewhere to the tremendous potential that lies in meeting the emotional needs of the retarded. In so doing, not only will their lives be enhanced, but other programs and technologies may move ahead more effectively and humanely toward more meaningful habilitation. Remember, as you read these articles, that none of us are suggesting that other programs and approaches be put aside; simply with these realizations that a more balanced and eclectic approach be assembled. Others around the country have begun similar efforts to provide a broader-based treatment approach, as described by Hal Benson in his article. I can assure you that the experience will be greatly rewarding to all involved!

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EMOTIONAL NEEDS OF PEOPLE WITH MENTAL RETARDATION:

A Preliminary Review

PAPER PRESENTED AT
THE ANNUAL MEETING OF
THE AMERICAN ASSOCIATION
ON MENTAL DEFICIENCY
Detroit, Michigan
May, 1981

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Introduction

In the broadcast sense, treatment of individuals with mental retardation has improved dramatically and steadily over the past 20 to 30 years. From the inhuman and emotionally crippling institutions of the nineteenth century there has been a metamorphosis to the current concern for the "person with mental retardation" and the need to provide an environment that is normalized and deinstitutionalized. Much of the progress that has occurred can probably be credited to the concept of normalization as put forth by Bank Mikkelsen (1969), Nirje (1970), Wolfensberger (1972), and others; and to the general concern for human and civil rights which flourished in the 1960's. Although there is now a growing question of the legitimacy of and practicality of deinstitutionalizaton and normalization for *all* residents (Partlow Case, 1979; Roos & McCann, 1977; Gunnwald, 1974), the basic principles from which those concepts were derived still permeate work with the retarded and still stand as goals or ideals to be sought. Essentially these principles are that each human being should be treated with dignity, regarded as an individual with individual needs, and be enabled to reach his or her optimal potential as a human being.

The above principles, which have affected the lives of millions of people in such a fundamental way, imply that the *whole* individual, with a myriad of needs, must be considered. These needs include physiological, cognitive, affective or emotional, and social. Despite the implication that the needs of the *entire* individual be recognized in treatment, one area has been seriously neglected in the literature and, one can assume, in treatment. This is the area of emotional growth and development. (Robinson and Robinson, 1967; Zigler, 1973; Stacey and DeMartino, 1957; Szymanski & Tanguay, 1980). Whether this area is not studied due to logistic difficulties, disinterest, ignorance or frustration, (Robinson & Robinson, 1976) the net result would be the same: the "emotional needs"[1] of individuals with mental retardation continue to receive disproportionate attention from professionals in the field, both in treatment and research.

It would be tempting to assume that so little is written about the emotional needs of individuals with retardation because there is no basic difference between their needs and the needs of the non-retarded. In fact, several people have postulated just that (Fisher, 1973; Phillips, 1967; Ayers & Duguay, 1969; Kessler et al, 1969).

However, a preponderance of literature, particularly that of behavior management, seems to imply or actually state that needs and drive of the organism are not important in treatment. In fact Skinner repeatedly asserts that behavior is the only worthwhile consideration, and that concern over motivation, internal drives, etc. is not an efficient use of time, (1953). Since behavior management is a primary treatment model for people with mental retardation especially in institutions, it seems reasonable to assume that their internal processes are unconsciously or worse, systematically, ignored.

It may be a mistake to assume that the emotional needs of those with mental retardation *are* the same as for the non-retarded. And if the *needs* are indeed the same, does this mean that *treatment* should be the same? Given the intellectual difference which is definitive of mental retardation, and the economic and environmental disadvantage that is often associated with retardation, *how* can treatment best be provided which meets all the needs of the individual with mental retardation . . . including his/her emotional needs? These are difficult questions, but the answers are critical to the lives of so many, that answers *must* be sought.

This paper is one result of two years of discussions, debating and investigation by the Emotional Needs Committee at Western Carolina Center in Morganton, North Carolina.* The Emotional Needs Committee was formed by a few individuals who felt that although residents' cognitive processing and skill acquisition were highly valued by staff, the emotional needs of the residents were usually not recognized. Further, that when the emotions of the residents *were* recognized, many people felt philosophically that they were of no value in the treatment process. In short, the emotional needs of the residents were being ignored.

Method

After a series of open discussions with a large variety of Center staff, the Committee was able to formulate some basic hypotheses regarding the needs of retarded people. An ongoing literature search was then undertaken to learn from the experiences and thinking of other professionals in the field. Briefly stated, the hypotheses under investigation were:

- People with mental retardation have the same basic emotional needs as non-retarded people.
- People with mental retardation need to develop self-acceptance (positive self-concept).
- They need to have *successful* life experiences in order to develop a positive self-image.
- The overall quality of the environment must be positive and rewarding, appropriately stimulating and secure (e.g. consistent; realistic expectations), in order for the individual to develop trust and to achieve maximal developmental, social and emotional growth.

*Western Carolina Center is a state institution which serves approximately 500 mentally retarded individuals, many with multiple handicaps, spanning all age ranges and functioning levels.

- People with mental retardation must develop trusting relationships in the significant others in their lives in order to be secure.
- Other important needs for healthy overall development include the need for privacy; autonomy (to the greatest extent possible); sexual dignity; effective communication skills; and basic physiological needs (i.e. food, water, shelter, warmth, freedom from pain and discomfort).

The literature search was initiated by accessing several computer retrieval systems on a variety of topics relating to the emotional growth, development, and needs of individuals with mental retardation as well as of normal individuals. Although the process is ongoing it is felt that a preliminary report is appropriate at this time, because the needs are so pressing and vital. The authors hope that this initial report will stimulate further investigation and interest; and that it can help bring about changes in attitude, philosophy and service delivery that might otherwise have been delayed.

In the following pages, important aspects of normal emotional development are summarized briefly, then emotional needs of individuals with mental retardation and the similarities to normal emotional development, are discussed. Following this is a summary of various treatments that have been used to enhance the fulfillment of emotional needs in individuals with mental retardation, and some implications of those treatments. Finally, the authors discuss and summarize their perception of the critical issues in treatment of the person with mental retardation and try to put these issues in proper perspective.

Normal Emotional Development

There are many theories of emotional development and each theory has its own particular emphasis. There is not complete agreement, nor could there be, regarding the different aspects of emotional development, personality or behavior. Different theories become more or less popular in professional and lay circles for awhile and then are replaced or modified by others that seem to own the spotlight, but then move on. There are, however, some basic concepts that have been fairly well accepted and are in some sense common denominators of all the theories.

The first well-accepted principle of emotional development is the need for primary/nurturing relationships. Numerous studies have cited the emotionally crippling effects which ensue when such a relationship is missing. For instance, in a classic study involving infants in an orphanage, those that received nurturing, tactile contact with nurses lived. Those that did not receive this attention often died. (Spitz, 1945, 1946) In a study with monkeys, it was found that those that received food from a simple mechanical apparatus developed anti-social, self-destructive behaviors. Those that received food from a warm, cuddly, soft "surrogate mother" apparatus were free from these behaviors. (Harlow & Harlow, 1970). Other research regarding "bonding" or "attachment" also verifies the need for positive relationships. (e.g. Bowlby, 1969; Ainsworth & Bell, 1970; Sroufe, 1977).

A second basically accepted concept in emotional development theories is that of *self-concept*. An emotionally healthy individual has, or must have, a positive self-image. He must like himself and generally feel good about himself. If he does not he will not be capable of truly fulfilling relationships with others nor will he feel truly fulfilled or successful as an individual.

It is generally accepted that children learn at an early age (e.g. less than two years) to differentiate between positive and negative attitudes, facial expressions, etc. of those around them. (Spitz, 1965) Gradually, humans become more and more aware of the differences in the feelings of people around them. Concurrently they become more and more aware of the consistency and adequacy with which they are treated and with which their physiological and psychological needs are met. These perceptions regarding the feelings and behaviors of the significant others around them form the basis of the person's feelings about himself and his environment. In other words, they form the basis of the individual's personality and the foundation from which he or she develops methods to deal with the world.

The mentally healthy person will develop a generally positive attitude about himself and generally socially acceptable and functional means by which to deal with his environment. He will become more and more refined at dealing with life and will become more and more independent and secure in his dealings with his environment, other people and himself. This "normal" mentally healthy person will by no means be perfect, but he will be able to cope effectively with his own failure and shortcomings and will continue to grow and mature despite them.

In summary then, although there are many specific theories of emotional development and personality; a few common denominators include the need for *self-esteem;* for *primary, nurturing relationships;* for adequate means by which to meet one's own needs and deal *effectively* with his environment; and to grow in the *security* of this environment to some level of maturity and success despite his or her shortcomings, weaknesses and failures.

Emotional Needs of the Mentally Retarded

To what extent are the emotional needs of people with retardation the same as those of non-retarded people? The literature surveyed to date indicates that there is no reason to believe that the needs are any different. Satisfaction of the needs, however, is often more difficult due to intellectual and communication difficulties, as well as to various other physical handicaps that often occur in people with developmental delays. (Phillips, 1967; Hofstatter & Hofstatter, 1969; Szymanski & Tanguay, 1980) Zigler[2],

[2]The reader is directed to Zigler (1973 and 1979) for a review of the empirical research re: personality development of individuals with mental retardation.

whose work is a notable exception to the general lack of empirical research in this area has stated (1973): "it would be more parsimonious to view the development of the personality of the retarded as no different in nature than the development of personality in individuals of normal intellect". (p. 240) He cites the following factors as being particularly important contributors to the relative lack of motivation in many individuals with mental retardation (1966): social deprivation; institutionalization; past negative experiences with adult caregivers; and frequent failure at attempted tasks. (p. 103-104). These experiences, when they do occur among people with mental retardation, have the same essential effects that they have on non-retarded individuals. Zigler (1973) hypothesizes ("motivational hypothesis") that these experiences contribute to behaviors that others have interpreted as a result of cognitive impairment alone (pp. 235-236). Zigler (1966) does point out that his work has suggested several tendencies which frequently occur in individuals with mental retardation who undergo institutionalization or other social depriving experiences: increased desire for attention and approval by adults; higher positive reaction tendencies, as well as higher negative reaction tendency; increased wariness of adults; lower expectation of success; greater outer directedness (p. 103-104).

It seems convenient for this paper to make a distinction between levels of needs. Although this distinction is somewhat modeled on the Maslovian heirarchy, (Maslow, 1954) it also seems to be a sensible and natural way to organize the various needs. (Maslow postulates that the needs must be met in order. We are not necessarily making that assumption here.)

The most basic needs for anyone are the physiological ones. (Maslow, 1954; Anderson, 1976). One must be fed, clothed, kept warm, protected from physical harm and discomfort, etc. If there are deficiencies in any of these areas, the person will likely be sick or weak, if he or she survives at all. Certainly all people, whether retarded or not, share in the physiological needs.

Beyond the physiological level, there seems to be a group of emotional needs that are commonly cited as being vital for the retarded person. These include the need for *self-esteem;* warm, loving relationships, or just plain *love;* the need to be *accepted* by those around him, including peers and other significant people such as parents, teachers, cottage staff, etc.; the need to have *successful experiences;* and the need for *security*. (Kessler et al, 1959; Phillips, 1967; Paramasmeran & Sherma, 1968; Hofstatter & Hofstatter, 1969; Kaur, 1977) The need for security is sometimes further refined to include the need to be able to control oneself, or impulse control (Ayers & Duguay, 1969; Mahoney & Mahoney, 1976; Kurtz & Neisworth, 1976); and/or the need to have some *control* over one's environment, including the people in it. (Power & Marinelli, 1974).

At a higher, or more complex level fall such needs as the needs for self-actualization, and self-understanding (Maslow, 1954; Roos & McCann, 1977). There is also a good deal of literature dealing with the concept of normalization (Wolfensberger, 1972, etc.) which stresses the need or right of individuals with retardation to lead as full and independent lives as possible, and to be enabled to reach their optimal potential. As stated in the introduction, this last body of literature, and the commitment of the people involved in the normalization movement, is largely responsible for many of the highly significant improvements in services for people with mental retardation which have occured in the last ten years or so.

It appears clear that the emotional needs of people with mental retardation, discussed in the articles and books surveyed to date, are virtually the same as those of the non-retarded people. We all need to have our basic physiological needs met; we all need to feel good about ourselves *(self-esteem);* have *warm, loving relationships;* be *accepted* by those around us; to have *successful* experiences; to have some *control* of our environment and ourselves; to feel *secure* in our environment; and to strive to reach our *optimum potential* intellectually. So far unstated, but implied in this entire discussion, is the notion that to the extent that these critical needs are met the person will be satisfied with their lives. To the extent that they are not met, the person will be frustrated. If this notion is accepted, then emotional needs of individuals with retardation *must* be met if we as a society value their potential actualization. We must strive, therefore, to help them meet their emotional needs, as well as to achieve success at vocational and academic activities.

Treatment Implications

Various efforts have been made to assure that the emotional needs of people with mental retardation have been met. Most studies have centered around the notion of increasing self-esteem and/or providing experiences in which the participants can be successful. A few have sought to facilitate positive, warm relationships; and a few have sought ways to improve the individuals' ability to communicate their needs or feelings in order to increase their feelings of acceptance, self-control and/or perception of independence.

Virtually all of the treatments so far surveyed have been tried only on a limited number of people and most have not had attempts at replication. Most have been done as active therapy rather than as part of a research design. Consequently, there is little hard data to indicate the efficacy of any particular method as compared to any other. There is also a relative paucity of literature in which specific techniques or methods of treatment are discussed, when compared to the vast amount of literature that has been generated in other areas regarding mental retardation. (e.g. behavior management, cognitive and educational areas, medical concerns, sociological aspects, etc.) The fact that the literature is so scarce cannot be taken as an indication that the various methods are not effective or not relevant. In fact, most of the literature reports some

success in the areas discussed. In some cases, the effects were temporary or did not generalize to other surroundings, in others the effects seemed to persist, and did generalize. If the methods were not effective and had been studied to any extent, one would expect to find literature indicating these attempts, but this is not the case. Consequently, the relative lack of articles is assumed to be a result of those issues cited in the introduction: logistic difficulties, lack of resources or interest, ignorance, etc. Regardless of the method used, however, there seems to be consistency between the *goals* sought and the basic needs discussed earlier.

Following is a brief summary of the treatments which we have found that have been attempted. As our project continues we hope to publish a more expansive description of some of these techniques. The authors hope the literature reported below will be used as a basic outline for future treatment methods and research designs; and, perhaps more important, as a source of inspiration and encouragement to conduct such treatments and research. Also included is a brief summary of literature specifically related to self-concept and the mentally retarded.

The methods used can be organized conveniently into five main categories: 1) Psychotherapeutic or counseling activities; 2) Therapeutic Arts; 3) Various activities to increase internal control and autonomy; 4) Activities designed to increase positive, nurturing relationships; 5) Activities designed to increase affective communication skills.

1) *Psychotherapeutic or counseling activities* - Many writers have reported success using counseling or some type of psychotherapy. Lopez (1974) found play therapy to be effective with a blind mentally retarded boy. Novak (1977) and Humes et al (1969) urge the use of counseling for persons with mental retardation who have been or will be mainstreamed into public school, and cite the need to train school psychologists in these methods. Kessler et al (1969) found play therapy in groups of parents with their mentally retarded children to be a contributing factor to the parents being able to cope with their children in the family home. Kaufman (1974) recommends pastoral counseling as a viable treatment model for the retarded, and Sternlicht and Wexler (1966) recommended "cathartic techniques" in general. Phillips (1967) feels that the emotional needs of people with retardation are very similar to those of non-retarded people; and that threatment of non-retarded people including psychotherapy or counseling, should and can be used with those with mental retardation. Rosen & Rosen (1969) reported a positive increase in the feelings of self-worth of a group of mildly retarded adults after group counseling. Hofstatter & Hofstatter (1969) and Menolascino (1969) have used both psychotherapy and psychotropic medications to treat emotional disturbance in mentally retarded patients. The former study noted the high incidence of depression in mentally retarded residents of a state institution and the efficiency of the psychotherapeutic and psychotropic treatment in these cases. Both Selwa (1971) and Selan (1976) have used psychotherapy with retarded individuals and reported good results. Finally Szymanski & Tanguay recommend the use of psychotherapy as useful in some cases. (1980)

2) *Therapeutic Arts* - The use of art modalities as a treatment method for individuals with mental retardation, to enhance emotional needs and development has been significant in the work of several practitioners. Rubin (1974) used music therapy, Ogletree (1976) used eurythmy ("therapeutic body movements"), Klepac (1978) used sociodrama and Lovano-Kerr and Savage (1972) used a variegated art curriculum and all reported "good" results; expecially in building a more accurate and more *positive* self-concept, and often in other areas such as social interactions, and increased self-control. Bauer and Modaressi (1977) used a variety of activities, including rhyming, rhythmic repetitions, metaphor, mirrors, videotape and audio recorders in work with autistic children and found these helpful in establishing and building a nurturing therapeutic relationship and in obtaining emotional and social growth. Simpson & Mezney (1979) indicated that a "program of physical activity" yielded increased self-esteem. Wilson (1977) used several graphic art modalities in a therapeutic regimen with a severely retarded woman and observed major improvements in social and emotional areas, as well as serendipitous learning and increases in cognitive level. Similar results have occurred in the Western Carolina Center Fine Arts Department's work with mentally retarded persons from profoundly retarded to borderline, and from six years of age and up. Creative writing experiences have been especially valuable in fostering appropriate affective expression, building self-esteem and establishing therapeutic relationships (Stamatelos and Mott 1980a and 1980b). (The authors note that a special interest group has formed in AAMD regarding Arts Therapy, and that efforts are underway for this group to become a subdivision. This would seem a promising development that may yield important insights into the issues raised in their paper.)

3) *Various activities to increase internal control and autonomy* - Roos and McCann (1977) urge the need for mentally retarded people to become self-actualized and to have many opportunities to make choices in their daily lives. They stress that even in very low functioning people choices should be possible in such significant areas as food and mode of dress. They also discuss their concerns that a balance is needed between efforts to enable mentally retarded persons to achieve skills and efforts to make them become more confortable or happy (what they call hedonism). They suggest that the traditional concept that people with retardation should achieve their *maximal* potential be amended to one in which they would achieve their *optimum* potential. The authors also contend that mentally retarded individuals should not be automatically or arbitrarily required to attend workshops or other vocational placements, without careful consideration of *all* the

person's needs, including the need for autonomy. Further, they stressed that vocational training centers can and should facilitate opportunities for the mentally retarded to have choices and make decisions.

Power and Marinelli (1974) report that normalization principles can and should be applied in vocational workshops for mentally retarded people. They stress the importance of giving them more control and choice regarding workshop activity and the need to make these activities more varied and interesting. They suggest that in addition to a choice of activities in the workshop setting, people with retardation should have a choice whether even to attend the workshop. They also mention the significance of staff attitudes and expectations on the behaviors of the retarded persons with whom they work. Kurtz and Neisworth (1976) and Mahoney and Mahoney (1976) report work they did successfully teaching mentally retarded clients to use self-management and self-control techniques, respectively. Schultz (1977) reports the need for institutionalized persons to have opportunities for privacy, although his work was not directed specifically at retarded populations.

Bachelder (1975) reports that socially disruptive and destructive behaviors in the cottage were decreased in a group of mentally retarded teenage residents of Western Carolina Center when they were given increased status and control in a different setting. Schuster and Gruen (1976) reported that when residents experienced *failure* at various tasks they had lower self-expectations as a result.[1]

4) *Activities designed to increase positive nurturing relationships* - In addition to many of the above studies which involved relationship-building either directly or indirectly, several people have written specifically on this area. Robinson (1976) used "therapeutic tutoring" of mentally retarded girls by medical students and found increases in "job performance, and the ability to manage frustration and anxiety...". Kessler et al (1969) examined reactions to separation from significant others in severly retarded children and found that they regressed in general skill level after such separations. Lopez (1974) stressed the need for "therapeutic relationships" in work with retarded people and Luckey and Chandler (1968) reported on the positive social and other skills and improved self-concept which resulted from "enriched staff/patient interactions" in an institution for retarded people.

5) *Activities designed to increase communication skills* -This significant area has been grossly overlooked in the literature. However, Kaufman (1974) stressed the ability of mentally retarded persons to learn to express their emotions appropriately and the importance of pursuing work in this area. Cantwell and Baker (1977) reported a positive correlation between speech and language retardation and psychiatric disorders and Kessler et al (1969) urged that efforts be made to increase affective communication between retarded children and significant others.

Self-Concept In Individuals With Mental Retardation

Both Schurr et al (1970) and Lawrence & Winschel (1973) reviewed previous literature relating to self-concept and the mentally retarded . Both papers indicated that considerable controversy prevails with regard to research findings in the area. These reviewers reported a variety of scales were utilized in research germaine to the topic; however Lawrence & Winschel (1973) observed that the scales are not without problems of "validity and interpretation" (p. 311). This opinion is synonymous with Buros (1972). The primary instruments reported in the literature included the Laurelton Self-Attitudes Scale, Piers-Harris' The Way I Feel About Myself, the Tennessee Self Concept Scale, Lipsitt's Children's Self Concept Scale, and the Illinois Index of Self-Derogation. Other instruments included the California Test of Personality, the Adapted Bills' Index, the General Self-Concept of Ability Scale, and variations of the Q-Sort technique.

Self-concept research frequently focuses on correlates of the construct. These reviewers reported findings in the general areas of IQ scores, achievement, sex, age, and race. They found that studies indicated that "subjects with higher IQ's were found to have more positive self concepts" (Lawrence & Winchel, 1973, p. 312). However, several authors expressed opinions contrary to these findings, and yet others found that there was no relationship between self-concept and IQ.

In the area of achievement, it was reported that studies indicate that the more positive an individual's self-concept, the higher the level of achievement is likely to be. Some questions regarding the reciprocal relationship of these constructs was also raised. Relatively few studies were found on the relationship of sex, age, or race with self-concept. Limited findings showed that the self-esteem of girls were found to exceed that of boys, however, this covaried with the age of the group. (Lawrence & Winschel, 1973; Mallenby, 1973) Most of the studies utilizing age as a dependent variable used adolescents to the exclusion of other age groups. Generally, personal adjustment increased with chronological age. Relatively little research dealt with the issue of self-concept between racial groups. Studies showed no effect of race; a positive relationship between self-concept and vocational competence for black subjects; or a negative correlation for white subjects on these variables.

"Numerous investigators have been concerned with the ideal self or with possible discrepancies between reported self and ideal self" (Lawrence & Winschel, 1973, p. 313). Most studies indicated that the evidence is conflicting regarding the meaning of discrepancies between self and ideal self. Other studies seemed to imply that there were

[1]The reader is directed to Abramson, Seligman & Teasdale (1978) for a discussion of the "learned helplessness" hypothesis of depression and to DeVillis (1977) for a discussion of learned helplessness in people with mental retardation.

differences in the self-concept between educable retarded children and normal children and that these differences became apparent in the first year of school. Studies on placement "indicate that, with the possible exception of an increased feeling of academic adequacy, segregation does not appear to contribute to positiveness of self-concept among the retarded, and greater degrees of segregation may be relatively less positive in effect" (Lawrence & Winschel, 1973). A similar conclusion was drawn by Calhoun & Ellis (1977). Payne (1971) found that during a short term institutional residence, mildly retarded children experienced a reduction in their expectations of failure. Nash & McQuisten (1977), utilizing a clinical interview technique, studied 130 Trainable Mentally Retarded students in a semi-integrated high school setting. Their findings indicated that there were no significant self-concept differences between the semi-integrated and segregated high school groups. Similarly, Carvajal (1972), in a study of 100 educable mentally retarded adolescents, concluded that the integration or segregation of the student in the educational setting was not a significant variable in the development of the self concept of educable retarded adolescents (p. 239). Conversely, a study based on social comparison and group reference theories (Strang, Smith, & Rogers, 1978) suggests that mainstreaming does augment significantly the behavior of the retarded student.

Hayes & Prinz (1976) found in a study of 208 mildly retarded and non-retarded boys and girls that in simple motor tasks, failure had less of a negative effect on the retarded group than on the non-retarded group. In a study focusing on self-image in institutionalized and non-institutionalized retarded and normal children, Zigler et al (1972) found that within the 118 studied, the retarded and institutionalized groups had lower real and ideal self-images than did the normal and non-institutionalized groups. This is contrasted to the findings of Montague & Cage (1974) which indicated that there were no significant differences in the self-concept between the institutional and non-institutional groups studied.

Carr & McCaughlin (1973) reported that participation in an Adult Special Education Class seemed to improve the students' ability to rate themselves on various measures more similarily to the way they were rated by both peers and teacher. However, they stated that uncontrolled and unspecified confounding variables rendered invalid self-concept measure which "was specific and designed for the particular study". Though replete with methodological difficulties, this study is noteworthy in the attempt to employ a nonverbal assessment of self-concept. While such an approach demands considerable development, it is mandatory if lower functioning mentally retarded individuals with limited verbal skills are to be included in any comprehensive study of self-concept in mentally retarded persons.

Morena and Litrownik (1974) endeavored to evaluate the differential effect of observation learning on the self-concept of educable mentally retarded and emotionally handicapped children. Three standardized self-concept instruments were utilized (Coopersmith Self Esteem Inventory, the Nowicki-Strickland Locus of Control Scale for Children, and a defensiveness measure drawn from the self-esteem inventory); as well as three behavioral measures: performance on a risk-taking task, preferred choice on a chance/skill task, and delay of gratification. While the intervention strategy did not provide significant differences in the groups, the authors do provide cogent suggestions for future research. Furthermore, the effort to devise behavioral indices for the evaluation of the self-concept seems warranted.

The state of literature investigating self-concept in the mentally retarded is summarized in this remark from a paper entitled: "Self-Concept and the Mentally Retarded: Implications for Intervention" (Rosenkoetter, 1980): "The literature relating self-concept to the mentally retarded is characterized by disparity, contradictions, tenuous results, and invalid conclusions. A preoccupation with substantive issues before more basic methodological considerations have been adequately considered lies at the core of the problem. Consequently, definitive conclusions regarding the utility of the self-concept construct for intervention strategies in a mentally retarded population cannot be drawn. The challenge looms large, and the technology is at hand; the next step is to directly address the major methodological questions."

Discussion

The treatment areas which need to be pursued seem clear. In some cases, as described above, efforts have already begun. In others, there is a complete void. It seems to the authors that this must change. Study and concern for the emotional needs must take a primary place in the work done with mentally retarded people. It can no longer lag so pitifully far behind the rest of the interest areas.[1]

Of first concern should be efforts to assure and enhance the self-esteem of persons with mental retardation. Accurate assessment or measurement methods should be utilized. In some cases, especially with lower functioning people, no appropriate measure may exist. There is a need for a well-designed method to measure self-esteem in very low functioning individuals. It is also essential to develop better instruments to assess self-concept in mildly and moderately retarded persons. Since self-esteem is such a fundamental aspect of mental health, any work done with retarded people must *always* take into account the effects, both short-term and long-term, on self-esteem. From the literature reported it seems appropriate to state that our first two hypotheses have been verified. (see page 3) Several of the articles did relate the need to have positive, successful experiences, although this has not been a major area of study. It is common sense, however, as well as consistent with general psychological theory, that people must experience success and positivism in their lives in order to develop positive self-concepts. It is essential, especially in institutional settings, that retarded people not meet with frequent failure and frustration or rejection. It is commonplace in institutions to hear staff complain that certain residents are not progressing or that a certain program is ineffective, even though it has been tried for months. Aside from legitimate concerns over accountability and cost-effectiveness, it is the authors' contention that such experiences are extremely damaging to the retarded person involved. The Partlow case is a good example of such frustration on a large scale. The authors are by no means suggesting that attempts to teach retarded persons, to make their lives more interesting and fulfilled, should cease. However, the first priority should be efforts to increase self-esteem, with learning of specific skills secondary. We must be extremely sensitive and caring in working with retarded persons, optimizing their *positive* opportunities for learning and growth, while minimizing those events and demands which lead to frequent failure and frustration. In many cases, such an emphasis on the positive process and on allowing, but not forcing growth, will lead not only to improvements in meeting the emotional needs, but in acquisition of new skills as well.

The second major area of concern in meeting the emotional needs of retarded people, should be in assuring that they acquire and maintain positive nurturing relationships with significant others. To accomplish this, work must be done on at least three levels or types of relationships.

First, it is important that retarded people have supportive, warm relationships with their parents or parent-surrogates (i.e. caregivers). When we speak of normalization or deinstitutionalization, we must speak, almost in the same breath, of the consistency and quality of the "parenting" of retarded persons. In institutional or other settings where parents are not involved on a daily basis with the clients, major efforts must be made to provide appropriate alternatives. The Foster Grandparent program is a good example of this type service. However, direct care staff must also fill a surrogate-parent role. In the case of mentally retarded adults for whom appropriate parenting never existed or existed at a minimum, we must continue to provide surrogate parents.

The second type of relationship that is critical is the peer relationship. Efforts to enhance social relationships among the retarded should be a primary objective, especially in institutional settings. When transfers are necessary for logistic or developmental reasons, the effect on the individual's relationships to his peers should be taken into account and appropriate measures to assure continuity should occur.

Therapeutic relationships with counselors, psychologists, teachers and so on are also of importance. Such staff should be well trained in therapeutic communication and intervention techniques and should use these routinely. In addition to formal counseling or psychotherapy, such techniques include active listening, various arts therapies, play therapies, recreational activities, and so on. In general, such staff should actively seek to establish open two-way communication on both a cognitive and *affective* level with their clients. They should make the retarded people they work with feel accepted and trusted, treat them with dignity and respect, and give them as much opportunity for choice and control in the relationship as is feasible.

The area of contingency management is of particular interest when relationships are considered. Rogers (1951) is well known for his theory that people achieve maximal mental health through *non-contingent* positive regard from a significant other, such as a parent or therapist. The

[1]A fruitful method of approach may well be one which incorporates a phenomenological perspective. In fact, science as a whole, and quantum physics specifically (which is the vanguard of science) no longer rely totally on a traditionally "objective" analysis of data-based research (e.g. Zukav, 1979). Rather, in the phenomenological position, the observer is a participant in the phenomenological field of action (see Goldman, 1978 for a discussion of "participant observation" in human services research). Phenomenological investigation within the field of mental retardation is almost nonexistent. However, although not explicitly stated, some researchers' recent work reflects this view (e.g. Zigler, 1973; DeVillis, 1977). A phenomenological approach would reveal and/or elicit existential acts by persons who have mental retardation, which would help us create a conceptual framework through which we may better understand their development. We would then be in a better position to facilitate improvements in self concept, as well as other significant personality variables.

authors believe that is is critical that *relationships* not be used contingently. Since behavior management is such a widely used tool in work with retarded people, their mental health may have been jeopardized seriously by systematically training staff to use their attention, verbal interactions, physical contact, etc., solely on a contingent basis. The authors have observed that such "contingent relationships" often result in individuals who feel rejected, worthless and alone. Especially in institutions, this may be one explanation for the high incidence of depression reported by Hofstatter & Hofstatter (1969). A similar phenomenon has been observed at Western Carolina Center. Each individual must feel that he or she is valuable as a person, regardless of her/his behaviors. We are not suggesting that the use of behavior management be abandoned, however we feel that whenever behavior management programs are used, four factors should always be considered. First, the effect on the person's self-esteem and relationships must be taken into account and every effort be made to avoid using staff attention contingently. Second, behavior management programs should almost always be positive and success-oriented, rather than punitive. Methods of prevention, logistical changes in schedule and so forth should always be sought before punitive measures are used. Behavior management programs should also stress the development of *internal* controls and internalization of the goals sought in the individual involved, rather than externally applied *management* of that person. We believe that many individuals who are potentially capable of making choices are denied this *right* and the right to *learn* to make choices. Retarded persons can probably be *made* to do many things if we "manipulate" them properly. We do not feel this is the meaning of "reaching maximum potential", however. Programs which are designed to reduce a mentally retarded person's "non-compliance" to staff requests have the effect of reducing that person's autonomy and self control Although the immediate and short-term effects may seem to justify such programs, we do not believe that non-compliance, per se, should be punished, or attempts made to diminish it. Instead, the natural consequences of the person's decisions not to comply should take effect, whenever possible. This type of approach would put the responsibility for decision making on the retarded person in a more appropriate manner.[4]

Another way in which programming effects relationships must be mentioned here. There is general commitment among people who work with retarded persons to the concepts of normalization and deinstitutionalization. There also seems to be a growing concern for the involvement of families and for provision of services through the least restrictive alternatives. It is the author's belief that positive nurturing parent or parent-surrogate relationships are vital if these accepted concepts are to be pursued. Yet we also see a drive for formalization of goals and objectives and planned, written formal programs for training. However, there is a tendency to *over*-program and in so doing sacrifice an essential aspect of the emotional growth of retarded people, namely warm, nurturing supportive relationships. Programs which dictate specific consequences or interactions to be used under *all* circumstances, with no judgement or flexibility on the part of staff, lead to cold, mechanistic interactions and subvert the dynamic power of the therapeutic relationship. Additionally, the dictating of unemotional, calm administration of contingencies (such as are often recommended in Token Economy Systems) eliminates a natural opportunity for the modeling of appropriate affective and social behavior. "Formal Programs"* suggest rigid, cold, mechanical procedures which concern themselves with outward form or appearance and disregard internal processing. In the author's experiences such programming exists frequently, and fundamentally undermines goals of deinstitutionalization and the drive toward providing humanistic therapeutic treatment. We are not advocating wanton recklessness or irresponsibility on the part of staff or retarded persons. We do believe that we must recognize what formal programming does to relationships and the efforts to normalize; and try to avoid such programs through proper training of staff, redirection of program goals and priorities and provision of a more therapeutic milieu. In short, *programs* are not normal. Neither normal families nor normal relationships are programmed.

Several other factors should be considered in the treatment we provide for mentally retarded persons. We have discussed the concept of control previously but want to emphasize the importance of the person with mental retardation being given the opportunity to develop internal control. In many cases this will be a long arduous process, since retarded people have been so over-controlled.

The issue of control[6] is one of the main concerns of the President's Committee on Mental Retardation, which is preparing a report called, "Living Environments for the Mentally Retarded in the 1980's". The following quote is from the second draft of that project, which was written in January, 1981:

> Recommendation V: The quality of living environment and the manner in which it is managed and served must support the striving of mentally retarded residents for their optimum level of choice and self-direction, and at

*American Heritage Dictionary (1969) defines "program" as "any organized list of procedures; schedule..." and "formal" as..."pertaining to the extrinsic aspect of something as distinguished from its substance or material...characterized by strict or meticulous observation of forms...stiff or cold, ceremonious...done for the sake of form only; having the outward appearance but wanting in substance..."

[4]see references re: learned helplessness

[6]This discussion of control is taken from the text of a panel discussion presented by the current authors at the AAMD Conference in Detroit, Michigan, May 28, 1981 entitled, "Emotional Needs of the Mentally Retarded Individual."

the same time provide the necessary safeguards which their handicapping condition requires."

An implication of this statement is that all of the reasons for right to choice among retarded people, as well as among all people, must be tempered by the necessary bonding of *rights* and *responsibilities*. *All* retarded people *must* be guaranteed the right to choice - but their right to choice must be at a level consistent with their *ability* to make responsible decisions. The essence of the argument for the right to choice among retarded people must be three-fold: first, that people with mental retardation are not discriminated against and denied the right to choice arbitrarily or capriciously. The right to choice must only be denied if the person truly is not capable of making responsible decisions, in specific situations. Second, we must realize that making responsible decisions is a skill that must be learned - and we have an obligation to teach such skills and to facilitate the opportunities for retarded persons to make decisions in order to learn how to do so in a responsible fashion. Along with this, we must remember that there are an enormous number of ways in which we can allow even very, very low functioning people to make simple decisions. Third, in giving retarded people the opportunity to make decisions regarding issues of importance (such as where to live or work) we must realize that there are real *risks* involved, risks both for the client and for the staff working with them.

Fourth, we believe effort must be made on a broad level to enhance the communication abilities of retarded persons, especially in the affective realm. To do so, we must be willing to show some normal feelings as a model. Retarded people must be taught and encouraged to express their feelings; even, perhaps especially, when those feelings are negative or hostile. Again this will be a long arduous, probably painful process but it *must* occur if normalization is really to occur. Our experiences indicate that efforts to teach and *allow* development of affective communication are fruitful; but systematic, thorough studies in this area are needed.

We must also make major efforts to understand, tolerate, appreciate and respect the right and need of the retarded person to lead a dignified, expressive sexual life. McEwen (1977) stresses the need to learn about the attitudes of individuals with mental retardation regarding themselves as well as about sexuality. He also discusses the "social and political implications" related to sexuality, and the results of an attitude questionnaire in these areas distributed to college students. Schlesinger (1977) cites 9 points from *A Resource Guide in Sex Education for the Mentally Retarded* (1971), "in order to make a plea not to shut out mentally retarded persons from the area of human sexuality." (p. 117). He also refers the reader to a book entitled Human Sexuality and the Mentally Retarded (DeLacruz & LaVeck, 1973) for additional information. Fischer (1974) and Perske (1973) have advocated for a much more open and tolerant attitude towards the sexuality and sex behavior of retarded people. Our experiences suggest that we are still a long way from achieving this goal. Since the sexuality of *anyone* is a significant part of his or her life, we feel we must make concerted efforts and advances in this realm of life of the mentally retarded people whom we serve.

In reviewing our original hypotheses, we believe we have found support for all of them, although there is certainly room for elaboration, modification and further reflection. The conclusions we have drawn in this section and the recommendations we have made are based both on our literature search and our experiences in the field. We actively solicit feedback, criticism, debate and especially further investigation. We firmly believe, however that we must *act* to broaden the treatment model to stress fulfillment of emotional needs. If we do err in our judgement in some cases, we will learn. We believe the field must recognize the previous errors of omission of concern for the emotional needs and learn from these past experiences.

Perspective

In following through on the needs and concerns raised in this paper, it is necessary to take a proper perspective. The growth made in many ways in recent years must be continued in all areas, including educational, behavioral and so on. But it is time to mature *beyond* these areas and grow further in our ability to accomplish not only what we have already, but *more*. We must strive to treat each mentally retarded person as a total human being, with due attention and priority given to the emotional needs. Rene Descartes has said, "The main thing in life is not to be afraid to be human." Although there are risks involved, we must not be afraid to apply this adage to persons with mental retardation.

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17

INNOVATIVE MENTAL HEALTH PROGRAMS FOR PEOPLE WITH MENTAL RETARDATION

PAPER PRESENTED AT THE ANNUAL
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Introduction

The origins of the MHA are rooted in the 1909 formation of the Mental Health Association when Clifford Beers formed the National Committee for Mental Hygiene. Beers had himself been a mental patient and after recovery devoted his energies to helping others. He was greatly aided and encouraged in the development of his citizen advocacy organization by William James, the father of American Psychology.

In 1950, Beers' Committee and two other groups combined to become the National Association for Mental Health, known today as the National Mental Health Association. The Association remains the one nationwide citizen's organization concerned with all aspects of mental health and mental illness.

The original and continuing purposes of the National Mental Health Association are: to promote mental health, to prevent mental illness, and to improve the care and treatment of the mentally ill. The needs are so great, and the tasks so monumental, the Association decided long ago that it could make the best use of its resources by playing the role of the advocate rather than direct provider of services. Our 850 chapters and divisions, and more than one million citizen volunteers, work toward these goals through a wide range of activities in social action, education, advocacy, and information.

Despite the fact that mental illness is the most prevalent *and* costly of any illness, actually accounting for over half the hospital days spent in this country, the Mental Health Association ranks only 12th among national voluntary organizations in terms of overall national income. Considering the scope of the problem, the public financing of programs has been minimal. For instance, the Federal government spends annually about 3.6 billion dollars on health related research, but only 5% of this goes for research in the areas of alcohol, drug abuse, and mental health.

Since 1955, there has been a significant change in where people receive mental health services. In the mid-1950's, when the number of people in state and county mental institutions was at its peak, 77% of the services were being provided in inpatient settings. In 1975, when a policy of "deinstitutionalization" swept the country, this situation was reversed. 76% of the services were then being provided in outpatient settings and 24% in inpatient settings. On any one day in 1975, there was an average of 193,000 people in state hospitals, down from an average of 559,000 in 1955.

Unfortunately, "deinstitutionalization" caught many areas of the country by surprise. Many patients were released without appropriate planning and before community-based services were prepared to care for them. Many, particularly those with long-term mental disabilities, found themselves out on the streets with no place to live, no job skills, few social skills, and no means of support. Their inability to "make it" had previously been demonstrated by the fact that of the 376,000 people admitted to state mental hospitals in 1975, about 60% had been there at least once before. This statistic has held steady for several years. There are perhaps one million people who received this "revolving door" system of care, or lack of care. Their neglect has replaced the problem of "warehousing" seen twenty-five years ago, and they have become the major mental health care and treatment problem of today.

Population studies indicate that in the next few years the need for mental health services and the problems of treatment and care will increase. Many segments of the population, such as the elderly, the disabled, ethnic minorities, women, and others are now underserved or inappropriately served by the system. The NMHA is committed to reaching out to each and everyone of these groups with treatment and education and to addressing the needs of those most vulnerable to mental health problems.

We are here today to address the needs of one such group, those persons who are "at risk" by virtue of the fact that they have a predisposing condition...Mental Retardation. We would like to share with you some innovative programs and concepts tailored to their needs, and to present our prognosis of future services to this previously neglected population.

According to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-111) the essential features of mental retardation are (1) significantly sub-average intellectual functioning, (2) resulting in, or associated with, deficits or impairments in adaptive behavior, (3) with the onset before age 18. The diagnosis is made whether or not there is a coexisting mental or physical disorder. Mental retardation and mental illness are separate and distinct conditions. Most persons with mental retardation are *not* mentally ill, although research indicates that organic brain damage increases the risk of emotional problems by two to three times that of the population at large.

Also, according to DSM-111, the prevalence of mental retardation at any given point in time is approximately 1% of the general population. AAMD statistics approximate that there are about two million readily identifiable mentally retarded persons in the United States. These are primarily the moderately and severely retarded, with some low functioning mildly retarded people also included. Another four million persons will be identified as mentally retarded at some time in their lives, usually during their school years. The vast majority of mentally retarded persons live *at home*. Mentally retarded persons constitute about 60% of all persons in sheltered employment. According to Department of Labor studies, the vast majority of work activity center clients are mentally retarded, and earn incredibly low wages, averaging 35¢ an hour. Current

statistics indicate that 60% of families with a mentally retarded member live under the standard "poverty" line economically.*

The condition is nearly twice as common in males as in females and seven to ten times more frequent in black and other minority groups than in white. The Federal Government is now spending an estimated $3 billion per year on mental retardation. Most of these funds are spent through major entitlement programs, SSI, and Medicaid. A *very* small amount is spent on prevention and research initiatives.

There are four sub-types of mental retardation reflecting the degree of impairment. They are designated: mild, moderate, severe and profound.

The emotionally disturbed mentally retarded individual is almost unknown in traditional mental health or mental retardation circles. Reliable data is scanty at best, and difficult to obtain. As a group, the emotionally disturbed mentally retarded have varying degrees of emotional disturbance as well as retardation, and their abilities to cope can change from situation to situation. The ED/MR person does not fall under traditional diagnostic and treatment classifications easily. Although it is difficult to get a clear picture of the mentally retarded individual with emotional problems, it is possible to properly assess his status, to develop a consistent treatment approach and regimen, and to implement a system of treatment delivery that addresses his needs and individuality. The most consistent feature of working with this population is that each individual is unique in terms of diagnosis, needs and responses to treatment. Mentally retarded persons suffering emotional problems respond generally much the same to mental health technology, properly adapted to their level of handicap, as those of the general population.

Research indicates that about 70% of persons with mental retardation have no need for mental health services per se. Of the remaining approximate 30%, most have no need for intensive or long-term treatment, but rather a limited mental health input in the form of counseling or therapy combined with a developmentally based program. This approach can assist the individual to resolve transient anxiety or depression, as well as initiate developmental processes that may have been arrested.

For those persons who are experiencing the more serious disorders, such as psychoses, a variety of specifically designed day and residential treatment programs are required. Working with these individuals can be a long process which requires a supportive, consistent, and thoroughly trained staff of both professionals and support personnel. Progress is often slow, regression frequent, and client resistance is not unusual and can also be severe. Treatment *must* be client-centered, flexible and innovative enough to allow for the needs of the client to be identified and met systematically.

When planning treatment for the emotionally disturbed mentally retarded individual, the most important initial step is knowing the individual as thoroughly as possible. An accurate history, an extensive intellectual assessment, and a sophisticated psychological profile must be obtained and integrated in the treatment planning and must reflect the unique qualities and needs of the individual.

Consistency is the most important variable when working with the emotionally disturbed mentally retarded client and is essential in terms of assessment, planning, and delivery of services. A systematic consistent approach to the provision of services must be the central theme of the staff as well as the program design. The message given to the client must be consistent from all the people in his milieu. A team approach is a viable means of insuring consistence across the board, as it helps secure staff support along with integrating a singular approach.

There is no single system of service provision that is universally applicable; the services need to be comprehensive *and* flexible so as to meet the individual's needs. The technology exists however, and the model programs have been initiated, but the full application of mental health technology is only partially developed toward meeting the needs of this long-neglected population.

The historic lack of adequate and appropriate services for those mentally retarded persons having emotional disturbances that often led to transient treatments, short-term placements in inappropriate settings, and in fact may have exacerbated their problems, are not the only options available. There are clearly problems which need to be addressed, and issues that need to be resolved before we will possess the viable models to provide alternatives to the past patterns of service.

Traditional mental health and mental retardation professionals and agencies have been loathe to claim responsible leadership or advocacy on behalf of the mentally retarded person with emotional problems. The fallout of previous skirmishes among agencies, professional groups, and service providers has been the neglect of the individual. The time has come when professionals from both fields need to establish initial linkages between people and resource systems. Stronger linkages between mental retardation and mental health systems, agencies, and professionals could ensure more appropriate and coordinated services for these individuals. At present, both systems suffer a paucity of trained and experienced people familiar with both fields. Much of the historic neglect of the emotionally disturbed mentally retarded persons can be attributed to the lack of sensitivity and familiarity of professionals about the facts and fictions of mental illness and mental retardation. Each system tends to perceive its clients in terms of services that system provides, and expects "the other" system to account for those persons who don't "fit" the mold, diagnostically or otherwise. The issue of "primary responsibility" becomes exclusive territoriality, and leaves the mentally retarded emotionally disturbed individual in service limbo.

There are, however, some treatment programs scattered across the country which provide us with innovative approaches to meeting the needs of emotionally disturbed

mentally retarded clients. Some of these programs we would like to share with you today, and we hope that they, along with others, can be utilized as model prototypes for promoting the mental health and welfare of a long-neglected population.

The National Mental Health Association strongly supports increased efforts to improve the delivery and accessibility of mental health services for mentally retarded persons and urges a broad commitment toward meeting the needs of mentally retarded persons and their families.

The final and future frontier in service provision will be the conclusion of this presentation. We firmly believe that the one best hope for meeting the future needs of such special populations lies in the prevention of mental illness. Special populations, such as the individuals with mental retardation, are "at risk" and prone to suffer a higher incidence of emotional disturbance than the population at large. We believe that the path toward amelioration of the mental health problems in these "at risk" groups is to prevent the problems in a primary sense, before they occur, rather than to allow the problem to arise, and subsequently to treat it. We are capable of accomplishing this with cooperation and research, innovation and information, and a joint commitment toward solution.

We would like to begin with a description of four programs which we feel are "innovative" approaches for service delivery to persons who are mentally retarded and have emotional disturbances. We have reviewed many more which employ similar technology, philosophy, and adapt to the unique needs of their select service population. In an Appendix we have included a list of other programs, not fully described in our main text. We have also acknowledged a number of persons who have assisted us in the development of this paper through material submitted, meetings, or telephone interviews.

We will begin today's discussion with a description of an innovative, on-going program at the University of Pittsburgh, known as the John Merck Institute. It will be followed by three other program descriptions, highlighting both the approaches and the unique characteristics of each. Finally, we will address prevention, especially primary prevention, which may be the light at the end of the tunnel for us. Considering the present economic and political climate, perhaps the most innovative concepts will come from the funding sector, and accountability will be the key password. Close scrutiny of the program in terms of "cost effectiveness" will be an increasingly stringent requirement. A new approach to subsidy may be a method not covered here that will be a first priority in today's and tomorrow's programmatic world.

John Merck Program for
Retarded Emotionally Disturbed Children

The program at the University of Pittsburgh Western Psychiatric Institute and Clinic was opened in January, 1975, and has been deficit funded by the John Merck Fund for the first three years. It has functioned as a pilot project demonstrating that, given appropriate staffing and individually designed treatment methods, it is possible to achieve substantial and lasting improvements in severely disturbed, brain damaged retarded children. The deficit funding made it possible to treat patients as long as it was clinically necessary. If hospitalization lasted longer than the limitations of third-party payors, the accrued deficit in payment for the treatment was covered by the grant from the Merck Fund. The Director of the program, Dr. Irene Jakab, identified the lack of financial constraints on the length of stay as one of the main ingredients to their success in treatment. Of the 105 children discharged during the past five years of operation, only two had to be readmitted. Seventy-five (75%) percent of those discharged have been integrated into their family and a local community school system.

During the last two years the program has been self-sufficient from patient/third party income. Dr. Jakab relates, there is, however, an increasing pressure to decrease the length-of-stay thus resulting in the discharge of patients who are, in their judgement, not ready to go. In fact, Dr. Jakab and her staff have witnessed some prematurely discharged patients "quickly regress" after discharge. They assert the patients' improvement had not solidified enough, and without the milieu, could not hold their gains.

The services provided by the John Merck Program include: complete diagnostic evaluation by multi-disciplinary team and consultants; and short-term and long-term partial hospitalization for psychiatric treatment and therapeutic education, including family therapy and/or social service for the parents. The child spends a full day or less, up to seven days a week, in the program. Residential intensive psychiatric treatment, complemented by skill development and milieu therapy designed to meet the individual needs of each child is provided, as well as speech and physical therapy if the need is indicated. Therapeutic education, tutoring, and rehabilitation for retarded children with language deficits and/or perceptual handicap due to brain damage is also provided. The multidisciplinary team reviews the treatment plan on a weekly basis. In the process of discharge planning, parents, schools, and appropriate community agencies are invloved and assisted by the staff in making long-range plans for each child. These plans assure continuous development and optimal reintegration into the community at the child's own level of functioning. Each child is recalled for a complete re-evaluation every three months during the first year following discharge from the program. Contact is also made with the school and any other mental health/mental retardation agency or physician involved at that time with the care of the child and/or the family. Following these re-evaluations, recommendations are forwarded on a consulting basis when necessary. In the second year, re-evaluations are made at six-month intervals and continue for four years.

Dr. Jakab believes that this style of an intensive program has proven to be cost effective. The program began with a high staff to patient ratio of 46 clinical staff to twenty patients (10 inpatients + 10 outpatients). After the first three years, the program's inpatient census has been increased to 22, and the day patients have decreased to 3. Services provided to the patients are quite expensive to the patients/third party payors, but the program seems to alleviate what might otherwise be long-term and ultimately much more expensive. The quality of life is also improved, thus tremendously benefiting the patient.

The John Merck Program provides special help for the traditionally unmet needs of children aged 3 to 12 years and their families. The therapeutic education and neuropsychiatric treatment developed and utilized in their model program is an innovative approach to serving the needs of persons with mental retardation and emotional disorders. It is a model of clinical services to this underserved population.

Program 2

Stone House

The State of North Carolina is currently attempting to provide more appropriate placements for heretofore "hard to place" persons. In North Carolina, persons who exhibit problems associated with both mental retardation and accompanying problemmatic behaviors are referred to as mentally retarded/behaviorally disordered (MR/BD) persons. At present, there are three pilot programs in the state operated by the Mental Retardation Services Section within the Division of Mental Health/Mental Retardation and Substance Abuse Services. These pilots attempt to demonstrate a model of service for MR/BD persons. The following is a condensed interim report of one of these programs, a group home model, which serves an age group of chronologically 16 years and older.

Stone House is a demonstration project operated and administered by the Wake County Area Mental Health/Mental Retardation Board. Funding for the program is provided by the Mental Retardation Services Section of the North Carolina Division of Mental Health, Mental Retardation, and Substance Abuse.

The purpose of the program is to demonstrate the efficacy of habilitating mentally retarded persons with accompanying behavior disorders and/or emotional distrubances in a group home setting. Physical aggression against other persons is the major behavior disorder on which this program focuses, although other disordered behaviors are frequently encountered.

The program is based on behavior management principles which emphasize the use of rewards to reinforce appropriate behaviors. Token systems are utilized with all residents. Primary reinforcement, activity sequencing and attention are frequently employed, as well as correction, over-correction, response-cost, and time-out procedures. Physical punishment, chemical restraint, and locked confinement are not used. Recently, progressive relaxation techniques and modified forms of systematic desensitization have been utilized with selected clients.

Opportunities for clients to develop and maintain skills in daily living, including food preparation and service, a variety of housekeeping behaviors, personal hygiene and grooming, clothing care, are structured for each client. Grocery shopping at local stores is scheduled twice weekly, and other shopping excursions are frequently planned. Clients are responsible for the care and cleaning of their own rooms, do their own laundry, prepare their own lunches, and assist in preparing, serving, and cleaning up after meals.

Other activities, such as recreation, education and prevocational training are provided. Counseling, both individual and group, is also available.

The families of clients are also given counseling and training in the management of behavior problems. Residents return home for week-end and holiday visits for at least ten days each year.

Outreach services, including training in the management of aggressive behavior, program development and on-site case consultation are available to other programs in the South Central Region of the state. Thus far, over 200 people, among them parents, law enforcement personnel, court counselors, public school teachers, and a variety of mental retardation professionals, have received training. On an outreach basis, seventeen mentally retarded clients have utilized counseling or specific program development assistance from the project.

The program is staffed with the equivalent of 11 full-time positions, including the director and a part-time secretary. At least two staff members are on duty at all times and are assigned to rotating day and night shifts. Two shifts are scheduled each day. The day shift begins at 8:00 a.m. and ends at 6:00 p.m. and the night shift begins at 6:00 p.m. and ends at 8:00 a.m. All positions, except the director, are entry level positions requiring a bachelor degree in a human service area. Prior to the opening of a project all staff received 5 weeks of training in behavior management and preventive intervention techniques (a physical defense program), and general principles related to the needs of mentally retarded persons.

Six mentally retarded clients with behavior disorders have been served in residence. Two clients are served in an after-school program, but continue to live at home. Four clients have been provided with counseling and behavior therapy on a weekly or bi-weekly basis.

Two clients who were in residence are now living successfully in another community residence. Another resident now lives at home except for four or five days a month.

All clients served by the project have shown significant declines in disordered behavior. Four clients who were previously excluded from day-activity programs are now making satisfactory progress in adult day-activity programs.

Program 3

The Rock Creek Foundation
for
Developmentally Disabled Emotionally Disturbed

The Rock Creek Foundation for Mental Health was founded in 1973 as a psychiatric facility to serve developmentally disabled persons who had serious emotional problems. It is the only intensive psychiatric treatment program in the Washington, D.C. area designed specifically for the treatment of those adolescents and adults who have simultaneous handicaps of intellectual deficits and severe emotional disturbances.

The three major components of the Center's services are: crisis stabilization, growth, and sustenance. This program is possibly the most comprehensive, and largest of its type at this time.

The admission criteria are liberal, requiring only that clients be able to function in a community setting because, as a voluntary agency, the doors must remain unlocked. The only rule against accepting a client is that he must not be *actively* suicidal, or homocidal. Another limiting factor is that funds must be available for care and treatment. Staff are available to assist in finding funding sources.

Activities take place at the Center from 8:30 a.m. to 5:00 p.m. with evening meetings scheduled for groups of day workers to come and discuss their problems.

Upon admission and periodically thereafter, each patient has an individual treatment plan drawn up to meet his particular needs. Various treatment modalities are utilized according to the patient's needs, and include: individual therapy, group therapy, family therapy, activity program, a vocational day treatment program and an outpatient vocational program.

Approximately twenty-eight to thirty-two patients may be enrolled in the current day treatment program. The program has few graduates; a graduate is defined as someone who has moved into full-time employment, lives in the community, and is no longer dependent on the Foundation for supportive functioning.

Day treatment was chosen over an inpatient setting as the most practicable, least expensive, and least disruptive modality. The concept of day treatment grew out of an awareness that the active treatment which occurs within the inpatient setting generally takes place during the eight or so hours when the majority of the staff are present. The other sixteen hours are primarily custodial care. By allowing the patient to go home and live in the community, there is less disruption of family life, less disruption of ties to the community, and a reduced risk of promoting institutional behaviors. Additionally, there is an increased opportunity to actively intervene in dysfunctional social systems, such as family or work situations, which disturb the patient. Finally, there is less trauma experienced by the patient at discharge, as he has never left the community of which he is a part. There is the additional bonus of reduced treatment costs, because staff and equipment requirements, including physical plant and supplies, are reduced.

A general description and rationale of the program modalities utilized at Rock Creek are as follows:

Individual Therapy: The therapy varies in length, frequency, and goals according to the needs and capabilities of the patient. Sessions usually vary in length between ½ and one hour, although some patients may be seen for ¼ hour at high frequency rates. They are usually seen between two and three hours per week. The goals of therapy are coordinated with the other work that is taking place.

Group Therapy: The therapy generally focuses on the feelings that the patients are experiencing at the time within the group. This technique operates on the widely accepted theory that feelings and situations which exist outside the group will be brought to and recreated within the group. The group process has the advantage of being able to use the example, the feelings, and the experiences of peers to assist a patient. Most patients participate in five to six hours of group therapy a week.

Family Therapy: This form of therapy is an extremely useful tool in working with the severely disturbed patient who is still dependent on his family for housing and subsistence. There are occasions where modification of the manner in which the family deals with a patient may modify the behavior of a patient. In all cases the method by which the therapy is executed builds on the strengths of the family and its members, emphasizing ways in which the patient can be encouraged to grow and realize his potential. In excess of 85% of the patients in day treatment are usually involved in some type of family therapy.

In each instance of therapy, the service is rendered by mental health professionals who are licensed within their profession by the State of Maryland and are psychiatrists, psychologists, psychiatric social workers, or psychiatric nurses.

Activities Program: The activity program of the Rock Creek Foundation includes most of the patients' activities outside of the various therapy sessions. The program utilizes a variety of techniques to

reinforce and build upon those functional, therapeutic experiences which take place in the more formal therapies. The techniques include: task-oriented groups, community meetings, dance and movement, and occupational therapy. These are designed to reduce dysfunctional behavior, increase self-esteem, reinforce functional thinking, and help establish a social network and reduce dependency.

For the patient who is not of school age, entry into the competitive job market is often essential to the successful completion of day treatement. With perhaps few exceptions, these patients have never held paying jobs or occupied recognized roles. It thus becomes necessary for habilitation, rather than rehabilitation, to take place before the patient enters the main stream of community living, many for perhaps the first time. The day treatment vocational program is consequently one which is carefully integrated into the treatment structure of the entire program.

The Rock Creek Foundation also provides a full spectrum of outpatient psychiatric services, including dianostic testing, individual, and group or family therapy. Psychiatric consultation under the direction of the Clincial Director of Outpatient Services is also available, in addition to an Outpatient Vocational Program, Work-Apprenticeship Program, Vocational Counseling, Work Adjustment Training, Job Development/Placement, and Post Employment Services and Adjunct Consultant Services.

Rock Creek Center has a unique, comprehensive array of services designed to meet the needs of adolescents and adults who are mentally retarded and emotionally disturbed. The opportunities provided within the program are indicative of the flexibility of the Center in meeting the individual's needs.

Harlem Valley Psychiatric Center

Harlem Valley Psychiatric Center is an example of a large psychiatric center comprised of an inpatient component and an extensive community support system network. Harlem Valley has about 500 patients and about 3,000 outpatients.

The present service design is the result of an intensive "deinstitutionalization" process which shifted the focus and orientation of service delivery from an inpatient custodial program to an open and integrated community network. During the process, Harlem Valley discharged large numbers of patients and curtailed admissions which reduced the inpatient population from 1,825 in 1974 to 523 in 1978.

As has occurred in other large public psychiatric centers, the first patients discharged from Harlem Valley were those who were the least disabled. Each successive group of patients was slightly more disabled than their predecessors. The process resulted in a remaining highly concentrated group of severely handicapped and multi-disabled inpatients. The need then arose to examine the nature and the needs of this inpatient population.

In October, 1978, the Harlem Valley Psychiatric Center applied for, and was awarded a Multiple Disabilities Grant of national significance from the Office of Developmental Disabilities. The purpose of the Grant was to develop a program model to repatriate developmentally disabled/emotionally disturbed residents of psychiatric centers by providing and linking resources between mental health and mental retardation/developmental disability service networks. The following objectives were defined for the project:

1. To identify those individuals with developmental disabilities who reside in or who are under the care of psychiatric facilities.
2. To assess the needs of this population.
3. To develop a service pattern, based on the needs assessment, designed on a continuum to greater independent functioning and normalizing community contact for the target population.
4. To develop mechanisms to link the programming continuum to the Harlem Valley Psychiatric Center's community support system and to the mental retardation/developmental disability service network within the facility's catchment area.
5. To evaluate the efficacy of the program model and to develop strategies for its replication.

The first stage in the identification of DD persons was a computer search for inpatients who had a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or other neurological impairment (federal DD definition). The second stage in identifying DD psychiatric inpatients was a review of the medical records of all patients identified in Stage 1. The purpose of this activity was to check for the origin of the disability prior to age 22, and to eliminate those patients whose behavior was attributable to medication side effects or resulted solely from institutionalization. This was necessary because almost all inpatients were older than 22.

A review of medical records was undertaken to determine the success or failure of the ability of this group to utilize deinstitutionalization resources available at HV in the past. These resources include opportunities for work, education, social activities, and activities of daily living training. Based on the skill deficits of the population determined during the assessment phase and the existing inpatient resources at the Center, this review was undertaken to evaluate the efficacy of existing programs in meeting the special needs of the population.

The main thrust of the service design for the core population was the learning and/or relearning of various skills in the identified areas of functioning. The primary approach was the utilization of learning theory and teaching constructs in the acquisition of such skills. A threv-tiered pattern was developed to assist the multiple disabilities population in moving closer to the goal of repatriation to more normalized community living. Each of the three tiers contained seven programming racks -clinical, educational, vocational, social recreational, daily living, medical, and residential.

Tier1 Inpatient Services: Programming was developed to concentrate on the direct teaching of desired skills through a structured learning method of active participation.

Tier2 Transitional Services: The transitional phase attempted to maximize the use of community resources on behalf of the patient population, to "normalize" activities and to assist the client group to move further along the continuum between the facility and the mental health/DD community support system.

Tier3 Community Services: This tier attempts to integrate the client group within the community support system of the Center's catchment area, with linkages to the MR/DD system wherever appropriate.

The ultimate objectives of the Special Services Team are to integrate multi-disabled clients into a full range of social and recreational activities sponsored by community support groups such as church and civic organizations, and to

formulate community-based programs which can become community collaborations supported and carried out by community volunteers.

Harlem Valley's Social Center is used by the Special Services Team as a focal point for programming. The programs are custom designed to introduce the client to leisure time activities on various levels. Programs are modified and adapted to the interests, needs, and level of function of the individual client, and are designed to be flexible enough for all. Included in the Social Center programs are a "Diner's Club" where groups meet and prepare their own dinners in a homey kitchen atmosphere and enjoy the elegance of eating their meal together in a formal dining room. Assisted by two SS Team member, clients cook, table set, clean up and practice table manners in dining together. Clients who graduate are entitled to participate in a restaurant dining experience in the community. A Diabetic Diner's Club serves even those on restricted diets and allows these clients the enjoyment of the full benefits of this program.

The Travel Bureau/Vacation program features day trips and mini-vacations to recreational areas both in and out of state. Camping, ski trips, and other travel experiences are afforded the clients in this innovative learning program. Clients enjoy excursions to New York City to attend Broadway matinees, dinner in a Manhattan restaurant, and various visits to choice landmarks.

An indispensable partner in the program is Harlem Valley's Office of Volunteer Services. The Office recruits volunteers from the community for participation in and/or support of the programs as they become working projects. The volunteer program includes a Family Host Program, a program of matching a volunteer to a client for a home meal, and family activities or outings.

The other portion of the volunteer program is one called the Community Experience Program, in which the volunteer participates with a client in a social learning experience. The volunteer accompanies the client into the community and familiarizes him with basic social skills, i.e., how to use a library, how to ride a bus, etc.

Many of these programs will be extensions of those provided in the Center, and others are recently innovated. Whatever the case, the goal is always to be supportive of the client in his effort to live a normal life.

As the gap widens between the demonstrated need for help and the costly, often unavailable, human resources to meet that need, we must recognize the futility of searching for a unique cause for every emotional disorder. It is likely that many disorders are a consequence of a variety of causation factors. We must recognize that widespread human distress can never be eliminated by attempts to treat afflicted individuals. We must also continue to do everything we can for persons suffering emotional disorders, while at the same time we must work toward eliminating the hazards to mental health.

Our promotion of preventive efforts will not attempt to displace or replace progress already achieved in intervention technology. Rather, we like to apply the best available knowledge, derived from research and clinical understanding to prevent the occurrence of emotional disturbance within populations "at risk".

As distinguished from mental health services designed to identify, treat, or rehabilitate persons already disturbed, preventive measures include those approaches that promote conditions reinforcing positive mental health, that promote and maintain competence, and that ultimately reduce the incidence of emotional disorders. Considering past reliance of mental health on corrective intervention measures, the concept of developing and applying preventive programs seems to be our greatest challenge and best potential for the future.

There are at least three substantial reasons to consider the preventive approach as a next step. One, there are too few resources to deal with the growing need for mental health treatments; two, the distribution of those limited resources is inequitable; and three, the present case of disproportionally allocating resources to the task of attempting to overcome "end-state" conditions or those most resistant to change. Logistically, there may never be a sufficient number of skilled providers to meet intervention needs, and historically, no major disorder has ever been eliminated from a population through one-to-one treatment, however comprehensive. From a purely economic standpoint, prevention offers the cost-benefit of substantial gains in lowering the incidence rather than increasing, over time, the long-run expense of treatment. At the very least, it would provide a stabilizing factor in the numbers of afflicted persons; a situation which does not appear feasible at the present time via traditional treatment programs.

Preventive measures have proved to be a vital extension of health care practices in physical health. Public health care approaches offer a sound conceptual and operational framework for undertaking prevention in the mental health field. Prevention in the field of mental health can be seen as the integrating perspective which would fuse our best understandings of the etiology of emotional disorders, family and group dynamics, and individual psychodynamics with a recognition of the salient social forces that combine to produce the disorganization we call emotional illness.

Prevention of mental health problems in the population of persons with mental retardation can begin with prevention of the predisposing condition—mental retardation. Mental retardation has some 200 known causes that precipitate the condition. Since we know that mental retardation as a predisposing factor increases the risk of emotional disturbance, and that the risk factors of the social environment have been tentatively identified in the general population as well as those within developmental disabilities, it would seem that we do have direction and impetus for establishing proactive prevention programming.

It is essential that all persons - persons with mental retardation, their families, the helping professions, and the general community - have a clear concept of what does and does not constitute mental illness within this population.

There is also a major task of recognizing and understanding the barriers created within society which prevent individuals with mental retardation from realizing their full potential. Life transitions, family relations, stigma, and the related stress of coping with these issues are key to overcoming mental health problems in this vulnerable population. The normal transitions from home to school to adult life can be expected to be more difficult and traumatic for mentally retarded persons, and assistance in coping with normal transitions may alleviate a great deal of suffering and prevent misdiagnosis of mental illness. Help-giving persons who are in frequent contact with mentally retarded persons should be offered training and supportive services in basic mental health skills so as to assist mentally retarded individuals in transition.

The family has been, and continues to be a vital resource, and families require a special sensitivity and understanding by helping professionals. Full consideration must be given to the kinds of supports that are necessary to sustain family vitality under the serious and recurrent problems that manifest themselves in this context. The problems of parental care and management of a mentally retarded child extend much further over the lifespan of a normal family. Programs of parent training and family education have already been initiated, and show promise of large gains to be made in the future toward preventing mental health problems of both the individuals with mental retardation and their families.

The preventive approach involves building the strengths, resources, and competencies of individuals, families, and communities that can reduce the flow of a variety of unfortunate outcomes. Because prevention strategies can be flexibly applied in a variety of situations, they are an especially attractive means for reaching the vulnerable,

high-risk groups, such as persons with mental retardation. Prevention strategies offer a different approach in that their concepts deal with populations and groups, rather than with individual cases. Preventive activities can be seen as the culminating effort to integrate past advances of intervention and the reduction of incidence within a population; a promise of reversal of the growing problem. As an example of the potential trend developing, we would like to mention a National Institute of Mental Health project currently underway.

The National Institute of Mental Health is sponsoring a project entitled: "Model Mental Health Programs for Mainstreaming Handicapped Children into Regular Classrooms". The major purpose of the project is to identify programs currently being used in schools to prepare teachers, parents, and students for mainstreaming. The project will also determine the factors successful in producing a classroom environment that fosters good mental health. The major product of the study will be a monograph describing some exemplary school programs. The expected release of this monograph will be in the Fall of 1981. This project should provide a wealth of concepts and factorial information that can be utilized in designing models for prevention in other settings as well. We would like to thank Jim Hughes and System Sciences, the grantee, for sharing this exciting prospect with us.

A variety of new and potential therapies for the retarded seems to be emerging around such fields as Holistic health, consciousness studies, bio-feedback, split-brain research, relaxation, imagery, suggestology and others.

In 1974, the Florida Division of Retardation spearheaded a symposium at the Unversity of Florida on the "Potential Implications of Non-Traditional Approaches to the Habilitation of the Developmentally Disabled." The President's Committee on Mental Retardation sent an official representative to the Florida Symposium and subsequently assigned a special investigator to look into innovative and non-traditional approaches.

The National Association for Retarded Citizens within the past 18 months sponsored a Symposium on Split-brain research and its implications for teaching the Mentally Retarded.

In 1980, a project funded by the National Institute of Mental Health resulted in a new book entitled "Health for the Whole Person, a Complete Guide to Holistic Medicine," published under the auspices of the Institute for Noetic Sciences.

The National Mental Health Association, at its National Annual Meeting in New Orleans, in November 1980, adopted a resolution which calls for the organization to support increased research and investigation of non-traditional treatment modalities.

An organization which is in the forefront in integrating new and traditional findings into new approaches for screening, diagnosing, treating and teaching the retarded, is the Institute for the Advancement of Human Services headquartered in Akron, Ohio. For more than a decade IAHS has worked to develop, field test, and refine new diagnostic, teaching, and therapeutic techniques, based on a "Whole Person" concept, with particular emphasis on mind-body interaction. A variety of validating field studies indicates that the Institute has achieved significant results with retarded clients as well as those with a variety of other disabilities, including the multi-handicapped.

Whereas most educational programs and prescriptive programs for retarded have focused on content and skills sequences in a number of competency areas, IAHS has focused on process and underlying prerequisite learning systems within the individual as a foundation for learning.

IAHS work, termed a "Learning Ecology" approach, provided a process for focusing on *how* an individual learns, rather than on content. The process is holistic, in that it brings the body and mind together on a learning task.

Finally, we at the National Mental Health Association would like to encourage those of you who are involved in providing such services to join us in sharing innovations and information through our Mental Health program exchange so as to promote nationwide efforts aimed at alleviating the tax of human affliction weighing on our fellow citizens. The costs of emotional distress in individuals with mental retardation, as well as others, cannot only be measured in terms of service costs. The final true measure is in the loss to society in terms of productivity, human dignity, and social dislocation that carries far greater imposition on our community than programmatic costs might suggest.

Appendix I

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Appendix II

OTHER PROGRAMS REVIEWED

HO'ONANE
Severly Handicapped Youth Leisure Time Training Project
University of Hawaii Department of Social Education
Bonnie Biel Wuerch - Project Director
1776 University Avenue UA4-7
Honolulu, Hawaii 96822
(808) 948-7778

A three year research project designed to develop curriculum for development of skills in leisure time activities which are age and developmentally appropriate as well as generalizable to school and home environments. A major focus will be on self-initiation, maintenance, and self-reinforcement toward independent constructive use of leisure time.

General Behavioral Interventions (GBI)
Orient State Institution - Pilot House
Orient, Ohio

The GBI's are the cumulative result of over two years of program development of the Interdisciplinary Team and recent research literature addressing the merger of cognitive and behavioral aspects of therapeutic intervention. The GBI's form the basis upon which a therapeutic milieu is created, in which the client population is encouraged to abandon adaptive, but socially inappropriate behavior patterns in favor of more appropriate behaviors. This program has been developed in the form of a handbook which facilitates consistent administration on behalf of the staff.

MR/BD Group Home Project
Wake County Area Mental Health Board
North Carolina

The primary goals of the MR/BD Group Home Project is to reduce the frequency and severity of aggression in each client to a level that will enable the client to return to community living. Data collected in the project indicate that the program is significantly reducing the frequency of aggression being emitted by the clients. The location of the program in a group home setting provides a wealth of meaningful, naturalistic opportunities for clients to acquire positive behaviors. Rewards for satisfactory behavior, including the accomplishment of tasks, consists of praise, recreational periods, coke breaks, and supervised outings. No chemical or physical restraints have been used to deal with client aggression, nor has aversive stimulation been used. In the face of a direct attack on themselves or property, staff utilize preventive intervention techniques (PIT) to protect themselves and the client. This technique has been used safely over one hundred times, without serious injury to clients or staff.

Home Intervention Plan
Chesterfield, Virginia

This program is designed to serve the MR/BD client in the community by taking training directly into the home for client, parents, and other family members. The model calls for working with each particular family for about three months, is progressive phases of about one month each. The first phase is intensive work with a family, observing and talking with them in the home environment, focusing attention on the environmental factors immediately preceeding and following the inappropriate behavior of the client. The second month is less intensive, and third moving the client and family to less dependence on the team. This is a very inexpensive program, requiring only salary and travel expenses for two staff members.

Project DATA: Demonstration of the Analysis of Transitional Activities
Nisonger Center for MR/BD
Columbus, Ohio

Project DATA focuses on the development of an educational model for severly and profoundly retarded students that will promote the generalization of adaptive behavior across stimuli, responses, people, language cues, and over time, enables students to make successful transitions to a variety of community residential, school, and vocational settings. The model focuses on : 1) development of learning environments that promote generalization; 2) analysis and evaluation of staff routine; 3) curriculum development; 4) family involvement in the educational process; and 5) planning and evaluation of student transitions.

Appendix III

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